

# NEW YORK STATE RARE DISEASE WORKGROUP

## AGENDA

July 18, 2023

11am-1pm

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- 1. Welcome by Workgroup Co-Chairs** *5 minutes*  
*Melissa Pittel Wasserstein*  
*Chief, Division of Pediatric Genetic Medicine*  
*Children's Hospital at Montefiore*

*Mary Wootten*  
*Member Coordinator, The Oley Foundation*  
*Volunteer New York Rare Action Network Ambassador, NORD*
- 2. Review of Agenda** *5 minutes*  
*Barbara Wallace*  
*Director, Division of Chronic Disease Prevention*  
*New York State Department of Health*
- 2. Awareness and Diagnosis Committee: Report out and Discussion** *45 minutes*  
*Laura Wuerth*  
*President, rareLife solutions*
- 3. Emergency Preparedness Committee: Report out and Discussion** *45 minutes*  
*Leslie Delfiner*  
*Co-Director, MDA Care Center at Montefiore*  
*Assistant Professor, Isabelle Rapin Division of Child Neurology,*  
*Saul R. Korey Department of Neurology*  
*Albert Einstein College of Medicine*
- 4. Open Discussion** *15 minutes*  
*All members led by Co-Chairs*
- 5. Closing** *5 minutes*  
*Melissa Pittel Wasserstein, Co-Chair*  
*Mary Wootten, Co-Chair*